

Communique

**Research Incubator
28 - 30 May 2024**



The Carer Knowledge Exchange team acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and Traditional Custodians of the lands where we live, learn and work.

About the CKE

The Carer Knowledge Exchange (CKE) aims to improve outcomes for carers by connecting research to practice. It brings together researchers, policy makers, practitioners and carers to share their knowledge and learn from each other.

The CKE began in July 2021 as a three-year partnership project delivered by Carers NSW and the Institute for Public Policy and Governance (IPPG) at the University of Technology Sydney. From July 2024, the project will continue, led by Carers NSW and funded by the NSW Government.

The CKE features:

- A growing, searchable **Research Library**
- Regular **events** and webinars
- Opportunities to **connect** with others

Find out more

To find out more about the CKE or to get involved, visit the digital platform at www.carerknowledgeexchange.com.au where you can:

- Subscribe for email updates
- Register for upcoming events and view recordings of past events
- Browse or add to the Research Library
- Read about caring and carer support services
- View lived experience focused resources via the Carer Hub
- Participate in the Discussion Forum

You can contact the CKE team by emailing research@carersnsw.org.au or phoning 02 9280 4744.

Introduction

The Carer Knowledge Exchange Research Incubator is an annual event that aims to identify and address the gaps in current carer-related research, policy and practice. The 2024 Research Incubator was held across six online sessions over three days from 28 to 30 May 2024.

The overarching theme for the 2024 Research Incubator was ‘Sustainability and caring’, with each session having a distinct focus. A total of 24 researchers, policy makers, practitioners and carers shared their expertise and knowledge through a variety of presentations and panel discussions, and findings were supported by strong data.

This communique highlights the main themes transpiring from the event, supported by direct quotes and data from attendees and graphical elements to effectively summarise the ideas from each session.



Emerging evidence

Researchers presented recent and emerging findings about carer finances and supporting diverse carers



Lived experience

Carers shared their experiences of accessing support and participating in innovative research and practice



Policy and practice

Presenters and participants discussed key challenges and opportunities relating to carer policy and practice



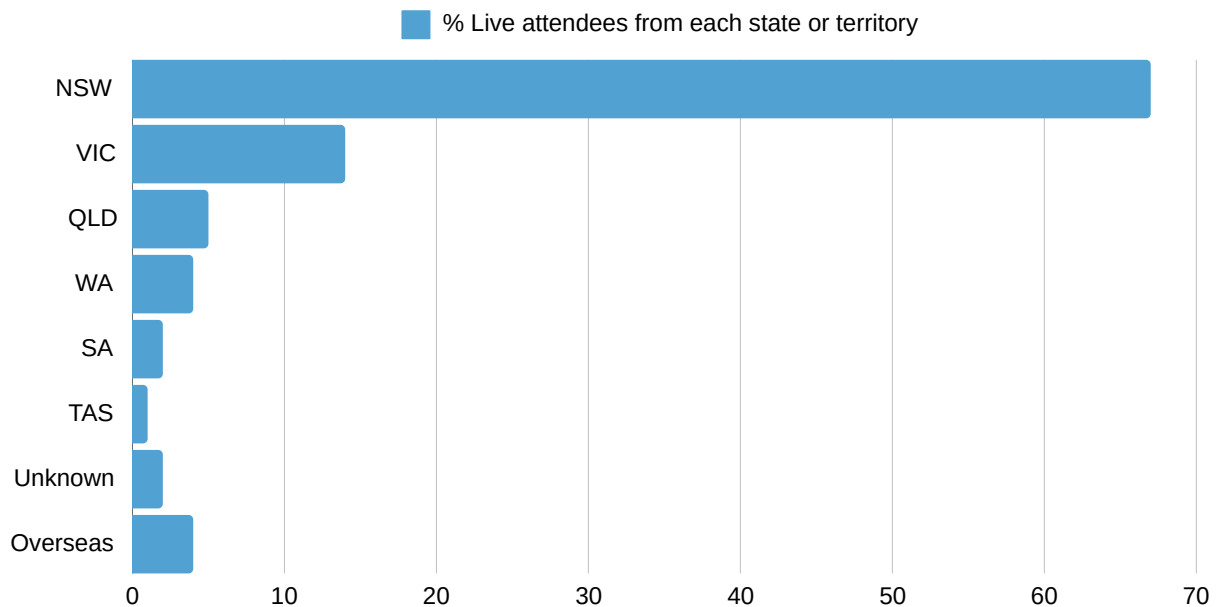
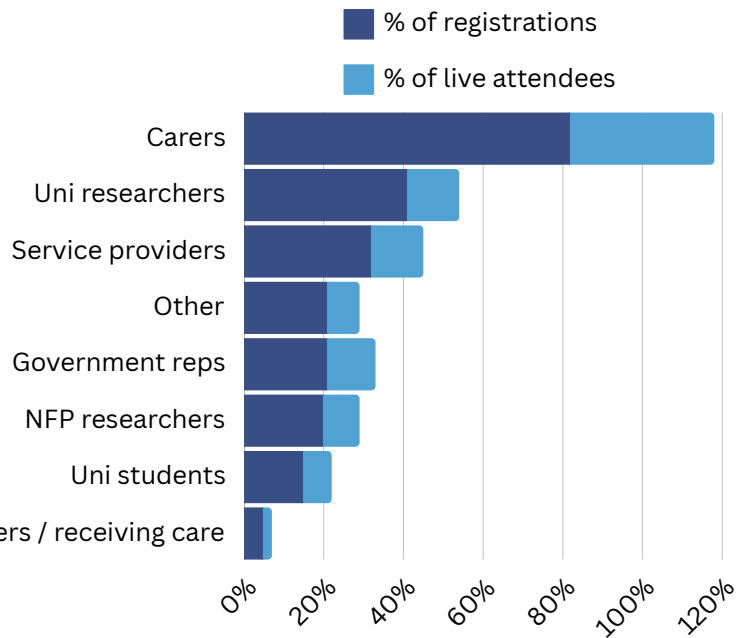
New connections

Researchers, policy makers, practitioners and carers shared their knowledge and learned from each other

Participants

A total of 169 researchers, policy makers, practitioners, carers, and stakeholders from 6 states and territories registered to attend one or more sessions.

Live attendance was at around 45% on average across the 6 sessions, with an average of 40 views on each session recording (to date).



Program

Day one: Sustainable carer support

Session 1: Panel - Culturally responsive approaches to supporting carer wellbeing

Session 2: Symposium - Innovative carer-led approaches in research, policy, and practice

Day two: Financial sustainability for carers

Session 1: Symposium - Building the evidence base on carer finances

Session 2: Workshop - What does financial wellbeing look like for carers?

Day three: Sustainable carer policy environment

Session 1: Consultation - Informing emerging carer policy

Session 2: Panel - Where to next for the Carer Knowledge Exchange?

Recordings from all the sessions from the CKE Research Incubator 2024 are available to watch on the '[Get Involved](#)' page of the CKE digital platform.

Findings

Analysis of the panel discussions, symposium presentations, breakout room discussions and participant feedback collected via Mentimeter identified eight overarching key themes from the event which are explored in the following pages:

- Carer wellbeing
- Carer recognition
- Social inclusion
- Cultural diversity
- Inflexible service systems
- Inaccessible information and support
- Financial hardship
- Gaps in research

Informing emerging carer policy

		
<p>The excessive reliance on carers to advocate for themselves without adequate support is a significant concern.</p>	<p>There is a strong need for recognition and remuneration for carers' efforts, and acknowledgment of the significant health impacts of caring.</p>	<p>Caring needs to be reframed as a public rather than private responsibility to enhance support and visibility for carers</p>

1. Carer wellbeing

Supporting carer wellbeing is critical to ensuring sustainable caring arrangements. Carers often lack the time, resources and finances to access support related to their wellbeing. This can be detrimental to their mental health and make them more socially isolated.

“We want to avoid carer trauma, grief, and loss as when this is accumulated this is when carers are unable to support their families.”

- Carer

“Parents often lack practical guidance and support to navigate through their child’s care journey...this guidance is crucial to address as it sets the trajectory for the family’s wellbeing.”

- Carer

“The lack of timely and appropriate support has far consequences for families and children, which is reflected within data.”

- Researcher

2. Carer recognition

Many carers do not identify themselves as a ‘carer.’ This can lead to carers not being recognised by others and to social isolation. Not using the term ‘carer’ can also prevent carers from accessing government benefits and services, which can put carers at higher risk of poor wellbeing and financial hardship.

Recognising carers and responding to their individual needs are critical in supporting carers to maintain their wellbeing and to continue caring sustainably.

“Many people may not identify as a carer...we need to plan for diverse types of carers.”

- Practitioner

“If you are not recognised as a carer by a government service, they miss out on eligibility such as carer allowance.”

- Researcher

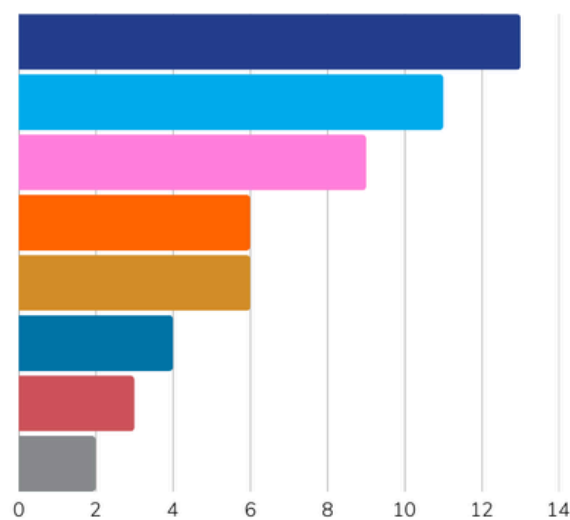
“Carers need recognition, they need understanding from policy makers that they need to be accommodated...”

- Practitioner

Participants in the ‘Informing carer policy’ consultation session were asked what the most important policy areas were to them. Carer rights and recognition was the highest rating policy area, followed by financial security.

- Carer rights and recognition
- Financial support and longer term financial security
- Employment rights and entitlements for carers
- How the term ‘carer’ is used and defined
- Access to carer support services including respite
- Aged care and disability reforms
- Secure and affordable housing
- Service navigation and advocacy

Audience policy priorities



3. Social inclusion

Social inclusion is critical to maintaining the wellbeing of carers. Many carers experience isolation due to reduced time and resources to connect with family members and friends. Stigma about caring can also contribute to this disconnection. Retaining existing, and building new networks and connections is key for carers to access support when they need it. Peer support groups and networks made up of other carers with shared experiences are a major source of support for many carers that can help to alleviate feelings of loneliness and isolation.

“Peer support can help reduce stigma, increase support, allow for the exchange of knowledge and promotes growth of community.”

- Carer

“Peer support has shown positive impacts on families...increased confidence in caring, a deeper understanding of resources available, and a keen sense of connection with others facing similar challenges.”

- Carer

4. Cultural diversity

Certain cultural groups feel a stronger obligation to care for family members, which can lead to reluctance seeking help from formal services. Language barriers can also reduce awareness of, and access to services. Although carers are diverse, carer policies and programs are not always flexible enough to accommodate these differences. Sometimes culturally diverse groups are treated as one category of carers with the same needs, rather than a range of groups with diverse needs. Understanding and responding to the needs of individual carers and specific cultural groups is important in providing effective carer support.

“Caring practices in culturally diverse communities are different due to language and cultural differences.”

- Researcher

“There is a strong cultural emphasis on family responsibility for caring and this is also observed in other cultures.”

- Researcher

Aboriginal and Torres Strait Islander communities consider intergenerational care an important part of kinship and maintaining their culture. Communities are often reluctant to access formal services due to prior negative experiences asking for help, both individually and collectively.

“Recognition and understanding of culture are vital to making change to policy, legislation and how we engage with people using our services.”

- Practitioner



5. Inflexible service systems

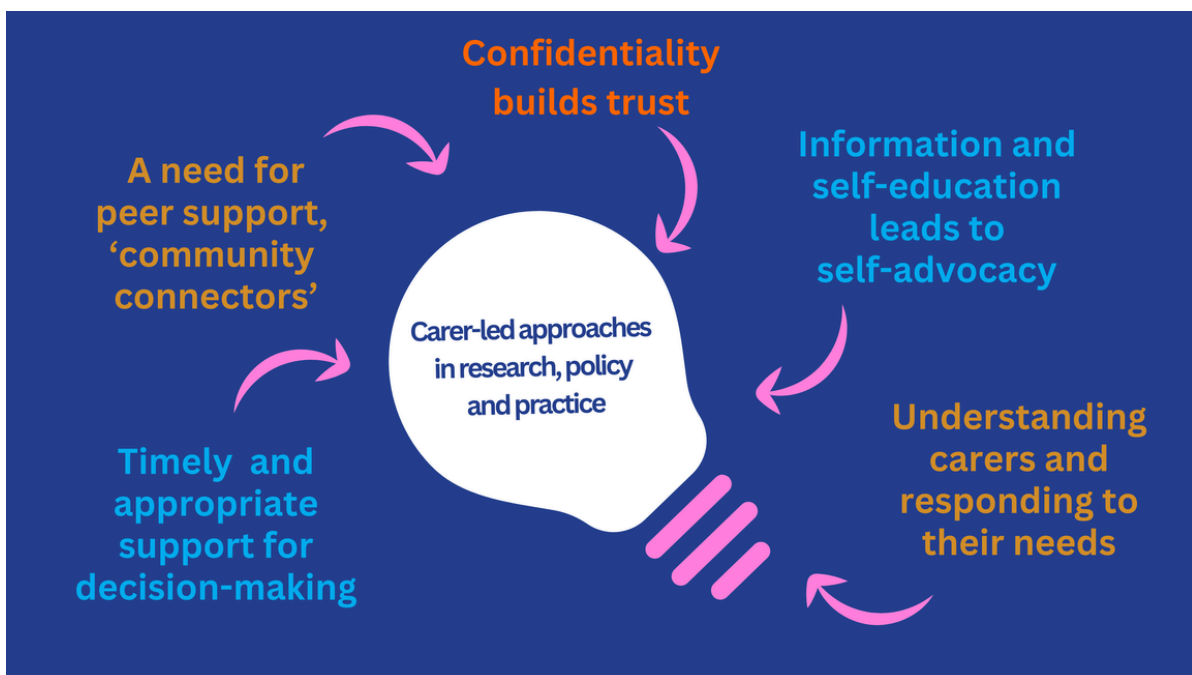
Service systems are not always able to adapt to diverse and changing needs. A 'one-size-fits-all' approach can discourage some groups of carers from seeking support, reducing their wellbeing. Person-centred support identifies each carer's needs rather than making assumptions based on cultural or other categories. It also allows support to adapt over time.

"We need to look at the flexibility and adaptability in the delivery of services within our systems."

- Practitioner

"What we need is systems that are reflective of the diversity and intersectionality of the cohorts we are trying to support."

- Practitioner



6. Inaccessible information and support

Accessing information about services and support can be very challenging for carers. Carers have limited concrete rights in service settings and are often unaware of the rights they do have. They can feel invisible to service providers, needing to constantly advocate for themselves and the people they care for to be heard. However, many carers lack the time, energy, confidence or resources to do so effectively.

“We need to move towards more integrated service systems that have better streamline access to information and support for carers.”

- Practitioner

“The lack of timely and appropriate support has far reaching consequences for both families and children, which is reflected within data.”

- Carer

“There is a lack of awareness that there are rights... a lack of inclusion and recognition of expertise in the broader community and workplace.”

- Practitioner

To address this, carers need education on how to access support and information and individual advocacy. Caring should be a shared responsibility, with carer wellbeing a priority for policy makers.

Carers and financial hardship



73%

have no emergency funds



57%

use buy-now-pay-later services



80%

depend on financial assistance



60%

spend more than a third of their income on housing

Cain, E. (2024) 'Financial impact of caring: Cost of living pressures on carers in NSW.'

7. Financial hardship

Carers often experience financial hardship because caring can involve additional costs and limit household income. Reduced income and superannuation can have long term impacts on families and result in psychological stress. While carers are often dependent on income support as a result, asking for financial assistance can be stigmatising.

"Financial sustainability is a central element of carer wellbeing."

- Practitioner

"The 2022 National Carer Survey revealed that 60% of respondents experienced some kind of financial stress."

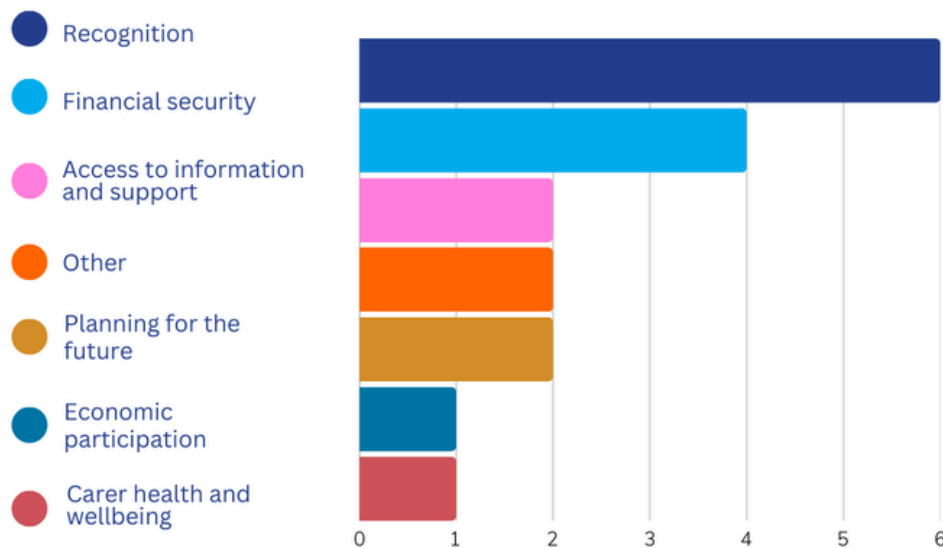
- Researcher

“Carers were more likely to seek some financial assistance in the past 12 months, significantly higher than the average at 80%.”

- Researcher

Mentimeter polls completed by attendees identified financial support and longer-term financial security as their second highest policy priorities.

Priorities: Next 12 months



8. Gaps in research

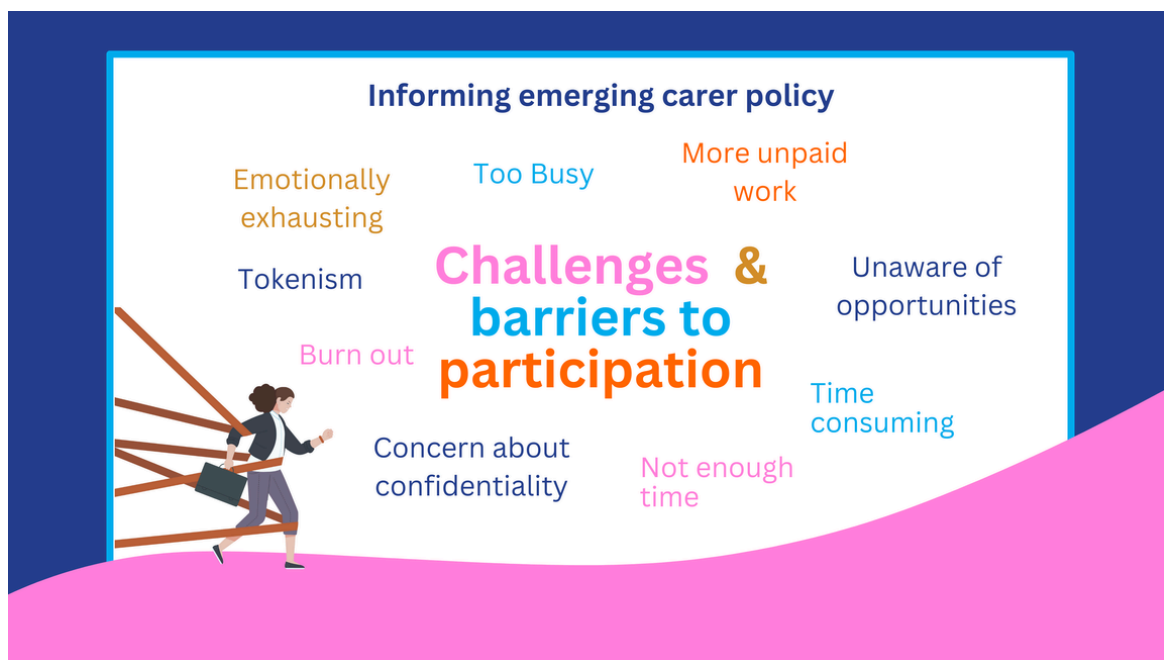
There remains a need to build the carer evidence base in a number of areas. More evidence is needed regarding the duration, frequency and long term impacts of financial hardship experienced by carers. There is also a lack of knowledge on how cultural matters affecting caring align with current policy and practice. It is therefore important that carers continue to participate in research so we can further evidence-based policy development and implementation.

"The impact of care on the carer remains very under researched and underacknowledged."

- Researcher

"We need more evidence on the population prevalence, and the duration and frequency of financial hardship."

- Researcher



Opportunities

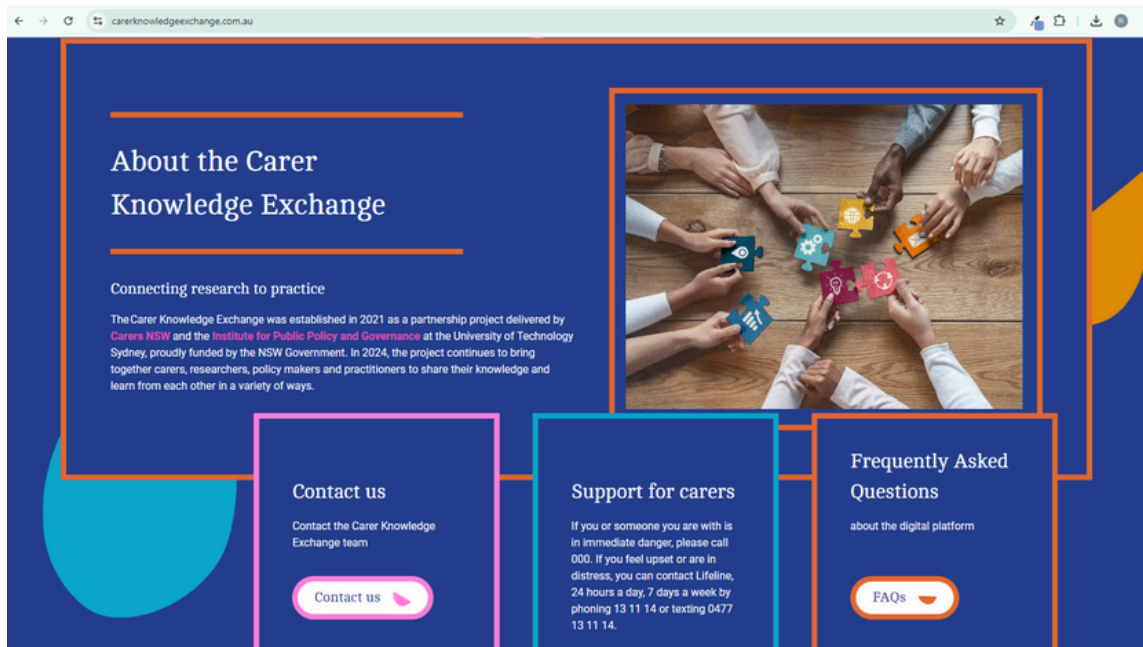
The findings from the CKE Research Incubator 2024 will inform the development and delivery of future CKE events and resources. Additionally, the following specific opportunities were identified:

- Build on and expand relationships with researchers from a range of networks and explore new opportunities for connection and collaboration
- Experimenting with new forms of engagement through different interactive events
- Bridging the gap between researchers and service providers/policy makers to carers and trying to make sure that carers become more involved within research design and implementation
- Challenging different community groups to think about how they approach research and how they work with communities



Get involved

To register for future CKE events, watch past event recordings, receive email updates, or participate in the CKE discussion forum, visit the **'Get Involved' page** of the CKE digital platform at www.carerknowledgeexchange.com.au or follow the Carer Knowledge Exchange on Facebook or LinkedIn.



For more information, please contact the Carers NSW Research team at research@carersnsw.org.au or on 02 9280 4744.